NPM #5: Percent of children with special health care needs age 0 to 18 whose families report the community-based service systems are organized so they can use them easily. (CSHCN Survey)

Impact on National Outcome Measures: According to the SLAITS Survey, 80.66% of families report the community-based systems are organized so they can use them easily. Families identified this as a need in the early 1990s and the Title V MCH/CSHCN Program responded by creating five Regional CSHCN Centers who provide information and referral, parent support opportunities and service coordination to parents of children with special health care needs.

a) Report of 2002 Major Activities

1. **Access to Service Coordination Services—Direct Health Care Services—CSHCN**
   The Regional CSHCN Centers provided various levels of service coordination to 3,642 families with a child with special health care needs who otherwise were not eligible for service coordination through other programs.

2. **Access to Information and Referral Services—Enabling Services—CSHCN**
   During 2002, the five Regional CSHCN Centers provided families 6,992 referrals to other agencies including programs such as early intervention, family support, and respite services.

3. **Community based services—Infrastructure Building Services—CSHCN**
   The CSHCN Program works collaboratively with many partners to assure children with specific diagnoses can access community-based services easily. These collaborative partnerships included the:

- Comprehensive School Health Action Council;
- DPI Parent Educator Project and WI FACETS, the Parent Training and Information Center;
- Wisconsin Asthma Coalition;
- Special Needs Adoption Program;
- Lead Prevention and Treatment Program;
- Diabetes Program;
- Wisconsin Infant Mental Health Association; and
- Early Hearing, Detection, and Intervention Program.

4. **Planning and implementing CSHCN projects—Infrastructure Building Services—CSHCN**
   Working in partnership with other funding sources, the CSHCN Program has participated in planning and implementing the following projects during 2002:

- Development of a tool for Birth to 3 Providers to screen children for nutritional needs.
- Development of a referral website for physicians to refer children identified with a birth defect to early intervention, a Regional CSHCN Center, and the LPHD.
- Provided funding to 46 LPHDs to conduct a local needs assessment focusing on CSHCN. Many identified a need for better knowledge of community partners for both providers and parents.

- Participated on the Children's Long Term Care Redesign Committee and the development of a functional eligibility tool for community programs to identify families to different community based programs based on one application.

b) Current 2003 Activities

1. Access to Service Coordination Services—Direct Health Care Services—CSHCN

The five Regional CSHCN Centers in conjunction with the LPHDs continue to provide service coordination to families with a child with special health care needs.

2. Access to Information and Referral Services—Enabling Services—CSHCN

The five Regional CSHCN Centers are continuing to refer families to community agencies including programs such as early intervention, family support, Katie Beckett, and respite services.

3. Community Based Services—Infrastructure Building Services—CSHCN

The CSHCN Program is continuing to work collaboratively with many partners to assure children with specific diagnoses can access community-based services easily. These collaborative partnerships include the:

- Comprehensive School Health Action Council;
- DPI Parent Educator project and WI FACETS, the Parent Training and Information Center;
- Wisconsin Asthma Coalition;
- Diabetes Program;
- Wisconsin Infant Mental Health Association;
- Early Hearing, Detection, and Intervention Program;

In addition, Wisconsin is participating in the MPKU Study regarding use of resource mothers (mothers of children with PKU). The research project is investigating if home visits by resource mothers improve the outcome of infants born to maternal PKU patients. Three women in Wisconsin have received training for resource mothers.

4. Planning and Implementing CSHCN Projects—Infrastructure Building Services—CSHCN

Working in partnership with other funding sources, the CSHCN Program is participating in planning and implementing the following projects during 2003:

- Provide TA to Birth to 3 Providers as pilot the Nutritional Screening Tool begins.
- Implementation of a referral website for physicians to refer children identified with a birth defect to early intervention, a Regional CSHCN Center, and the a LPHD.
- Provide TA to the LPHDs that conducted a needs assessment as they complete the projects identified as next steps including the development of a community resource map, a directory of local providers and the development of community consortiums to develop stronger partnerships within their community.

- Participate on the Children's Long Term Care Redesign Committee as it implements a functional screen eligibility program for families in select counties identified as pilot sites.
- The Wisconsin Council on Mental Health distributed a survey in 2003 to advocates and family members in order to identify the top issues of concern for families who have a child with severe emotional disturbance. Develop a plan to address the top identified needs of respite services, insurance parity and crisis services.

c) 2004 Plan/Application

1. Access to Service Coordination Services—Direct Health Care Services—CSHCN

The five Regional CSHCN Centers in conjunction with the LPHDs will continue to provide service coordination to families with a child with special health care needs.

2. Access to Information and Referral Services—Enabling Services—CSHCN

The five Regional CSHCN Centers will continue to refer families to agencies including programs such as early intervention, family support, Katie Beckett, and respite services.

3. Community Based Services—Population-Based Services—CSHCN

The CSHCN Program will continue to work collaboratively with many partners to assure children with specific diagnoses can access community-based services easily. These collaborative partnerships will include:

- Attend monthly Comprehensive School Health Action Council meetings.
- Attend regular meetings at the State and Regional Level with the DPI Parent Educator project and WI FACETS, the Parent Training and Information Center.
- Participate on the statewide WAC to implement an asthma action plan that expands and improves the quality of asthma education, prevention, management, and services, and eliminates the disproportionate burden of asthma in racial/ethnic minority and low income populations.
- Assist with the implementation of the Wisconsin Infant Mental Health Association strategic plan for WI addressing the areas of training, policy and public awareness around issues of infant and early childhood mental health.
- Continue to provide staff time and co-sponsorship to the Circles of Lie Planning Conference to offer opportunities for parents to gain knowledge of community based services.

4. Planning and Implementing Community Based Projects—Infrastructure Building Services—CSHCN

Working in partnership with other funding sources, the CSHCN Program will participate in planning and implementing the following projects during 2004:

- Statewide implementation of a tool for Birth to 3 providers to use to screen children for nutritional needs as well as develop a policy for how the children positively identified will receive the necessary nutritional services.

- Evaluate the five Regional CSHCN Centers to determine how best services can be provided to families in the next five year grant cycle.
- Be an active partner on the Children's Long Term Care Redesign Committee as the pilot sites implement community based waiver options for children.